

Predictors of Deceased Organ Donation in the Pediatric Population

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abstract

BACKGROUND: A shortage of donor organs represents the major barrier to the success of solid organ transplantation. This is especially true in the pediatric population for which the number of organ donors has decreased over time. With this study, we aimed to assess the factors associated with deceased organ donor consent in the pediatric population and determine the variability in consent rates across organ procurement organizations (OPOs).

METHODS: All eligible pediatric deaths were identified from the Scientific Registry of Transplant Recipients (2008–2019). The rate of organ donor consent was determined, and multivariable logistic regression was used to assess the factors independently associated with successful donor recruitment. The probability of donor consent was determined for each OPO after adjusting for patient demographics.

RESULTS: A total of 11 829 eligible pediatric deaths were approached to request consent for organ donation. Consent was successful in 8816 (74.5%) subjects. Consent rates are lower in the pediatric population compared with young adults and are directly related to patient age such that eligible infant deaths have the lowest rate of successful donor consent. There is significant variability in donor consent rates across OPOs, independent of population demographic differences.

CONCLUSIONS: OPO is predictive of pediatric deceased organ donor consent independent of demographic differences, with some regions having consistently higher consent rates than others. Sharing best practices for pediatric deceased donor recruitment may be a strategy to increase organ availability in the pediatric population.



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WHAT'S KNOWN ON THIS SUBJECT: A shortage of donor organs represents the major barrier to the success of solid organ transplantation and pediatric patients awaiting organ transplant demonstrate high mortality while waiting. The number of pediatric deceased organ donors has decreased over time.

WHAT THIS STUDY ADDS: The rate of successful donor consent differs between pediatric and adult populations. There is high variability among organ procurement organizations in pediatric donor recruitment that is independent of patient demographic differences.

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A shortage of donor organs represents the major barrier to the success of solid organ transplantation, leading to concerted efforts to improve the availability of donor organs. In 2003, the Organ Donation Breakthrough Collaborative was established. This effort identified best practices for organ donor recruitment, resulting in a >10% increase in deceased organ donation the following year.^{1,2} However, this increase was only realized in the adult population, and the number of pediatric deceased organ donors has in fact decreased over time.^{3,4} Currently, there is no standard approach to the recruitment of potential pediatric donors across the 58 regional organ procurement organizations (OPOs) in the United States. In fact, it is suggested in recent data that pediatric deceased organ donation rates are highly variable across the country with high- and low-performing regions.³

The overarching hypothesis of this project is that there is significant variability in pediatric deceased organ donor recruitment across OPOs that is independent of differences in donor demographics. Identifying OPOs that recruit pediatric donors at higher rates may allow identification of best practices for pediatric donor recruitment. Although OPO-specific reports are published by the Scientific Registry of Transplant Recipients (SRTR) to assess OPO performance, pediatric-specific donor recruitment has not been specifically addressed.⁵ The aim of this analysis is to assess the trends in pediatric deceased organ donor recruitment and to describe the variation in pediatric deceased donor consent rates across OPOs, after adjusting for demographic differences.

METHODS

For this study, we used data from the SRTR. The SRTR data system includes

data on all donors, wait-listed candidates, and transplant recipients in the United States, submitted by the members of the Organ Procurement and Transplantation Network (OPTN). The Health Resources and Services Administration, US Department of Health and Human Services, provides oversight to the activities of the OPTN and SRTR contractors.

The SRTR database was queried for all eligible pediatric (<18 years of age) deaths (January 1, 2008, to November 30, 2019). OPTN currently defines an eligible death as a person ≤75 years of age who is legally declared brain dead, has a body weight ≥5 kg, has a BMI ≤50, and does not have specific coexisting diagnoses (ie, active infections, malignancy).⁶ As a comparison group only, eligible adult deaths (ages 18–40 years) were also assessed by using the same SRTR data source. The age cutoff for this group was chosen to minimize donor comorbidities and on the basis of evidence that organs from donors >40 years of age portend worse survival for heart transplant recipients.^{7–9} Donor conversion rate is a commonly used metric that SRTR uses to assess OPO performance, measuring how often an eligible death becomes a deceased donor. Given the limitations of organ donor registration in the pediatric population, our analysis was focused on consent rates, namely, how often an eligible death approached for consent becomes a deceased donor. Although older adolescents can register as an organ donor, this is not legally binding and requires next-of-kin consent from a family member. This group was not included in the calculation of consent rates because family knowledge of organ donor registration may influence the consent process. Overall organ donor consent rates were calculated, and linear regression was used to assess the changes in pediatric donor

consent over the past 10 years. Consent rates were then calculated for each OPO and summarized by using descriptive statistics. Consent rates at the OPO level were compared across age groups and between pediatric and adult eligible deaths by using the Wilcoxon rank sum test.

Demographics of eligible pediatric deaths were compared between those who were and were not approached for consent and between those who did and did not consent to organ donation. The χ^2 test was used for categorical data and the Wilcoxon rank sum test was used for continuous data. Variables assessed included age, sex, race, ethnicity, circumstances of death, whether the referral was timely (defined by the Organ Donation Breakthrough Collaborative as within 1 hour of meeting an established clinical trigger, but specific definitions vary across OPOs¹⁰), and median household income. Race and ethnicity are self-reported by next-of-kin decision-makers. The median household income for each prospective donor was estimated by using 2010 US census data in conjunction with the subject's home zip code.¹¹ Although this represents an estimate at the community level, for the purposes of this article, this is subsequently referred to as "median household income."

A multivariable logistic regression model was constructed to assess independent predictors of successful consent for organ donation from eligible pediatric deaths. Variables included in the model were selected a priori and included OPO, year, age, sex, race, ethnicity, cause of death, timely referral to the OPO, and median household income. For subjects with missing median household income data ($n = 2146$; 18.1% missing), multiple imputation was performed accounting for subject age, death circumstance, race, and

OPO with 10 iterations according to approach found in Rubin and Schenker.¹² During the process of model refinement, cause of death was transitioned to child abuse etiology (versus other etiologies) to simplify model interpretation without altering the significance of other variables included in the model. All statistical analyses were performed in Stata version 15 (Stata Corp, College Station, TX) with 2-sided $P < .05$ considered statistically significant. SE estimates were adjusted for clustering of population demographics within OPOs. This study was approved by SRTR and the Vanderbilt University Medical Center (Institutional Review Board 192080) and Carnegie Mellon University (Institutional Review Board 19-526) Institutional Review Boards.

RESULTS

A total of 12 680 eligible pediatric deaths were identified for inclusion. Of this group, 331 (2.6%) were registered as organ donors and 11 829 (93.3%) families were approached to request consent for organ donation. Of those approached, consent was successful in 8816 (74.5%) subjects (Fig 1). A total of

TABLE 1 Donor Characteristics Based on Approach for Consent ($N = 12\,349$)

	Approached $n = 11\,829$ (95.8%)	Not Approached $n = 520$ (4.2%)	P^a
Age group, y, n (%)			<.001
<1	1894 (92.7)	149 (7.3)	
1–4	2863 (94.4)	170 (5.6)	
5–10	1901 (96.3)	73 (3.7)	
11–17	5171 (97.6)	128 (2.4)	
Sex, n (%)			.02
Male	7322 (96.1)	295 (3.9)	
Female	4507 (95.3)	225 (4.8)	
Race, n (%)			<.001
White	8129 (96.3)	310 (3.7)	
Black	3185 (94.6)	183 (5.4)	
Asian	280 (96.6)	10 (3.4)	
Other	234 (93.6)	16 (6.4)	
Ethnicity, n (%)			.41
Hispanic	2452 (96.1)	100 (3.9)	
Non-Hispanic	9377 (95.7)	420 (4.3)	
Timely referral, n (%)			.004
Yes	10 411 (96)	436 (4)	
No	1418 (94.4)	84 (5.6)	
Circumstances of death, n (%)			<.001
Motor vehicle crash	2505 (96.9)	80 (3.1)	
Suicide	1058 (98.5)	16 (1.5)	
Homicide	780 (96.7)	27 (3.3)	
Child abuse	1381 (91)	136 (9)	
Accident, not a motor vehicle crash	1901 (96.6)	67 (3.4)	
Natural causes	2526 (95.9)	107 (4.1)	
None of the above	1626 (95.3)	80 (4.7)	
Household income, ^b \$, median (interquartile range)	47 027 (37 901–59 801)	43 637 (34 024–52 752)	<.001

^a P values from the χ^2 test for categorical and the Wilcoxon rank sum test for continuous data.

^b Based on donor home zip code and 2010 US census data. $n = 9886$ (19.9% missing).

520 (4.1%) subjects were not approached for consent. Eligible deaths were less likely to be

approached for donor consent if they were <1 year of age (7.3% of donors <1 year of age were not approached versus 3.5% for older donors; $P < .001$); female sex (4.8% of female donors were not approached versus 3.9% of male donors; $P = .018$); Black or other race (5.4% and 6.4% for Black and other race, respectively versus 3.6% for white race; $P < .001$); from an area with a lower median household income (median income \$43 637 for those not approached versus \$47 027 for those who were; $P < .001$); if they lacked a timely referral to the OPO (5.6% vs 4%; $P = .004$); and if death was secondary to child abuse (9% versus 3.4% for other etiologies; $P < .001$) (Table 1). The likelihood of OPO staff approaching a potential donor was directly related to patient age (Supplemental Fig 5) ($R^2 = 0.75$; $P < .001$), such that families of younger

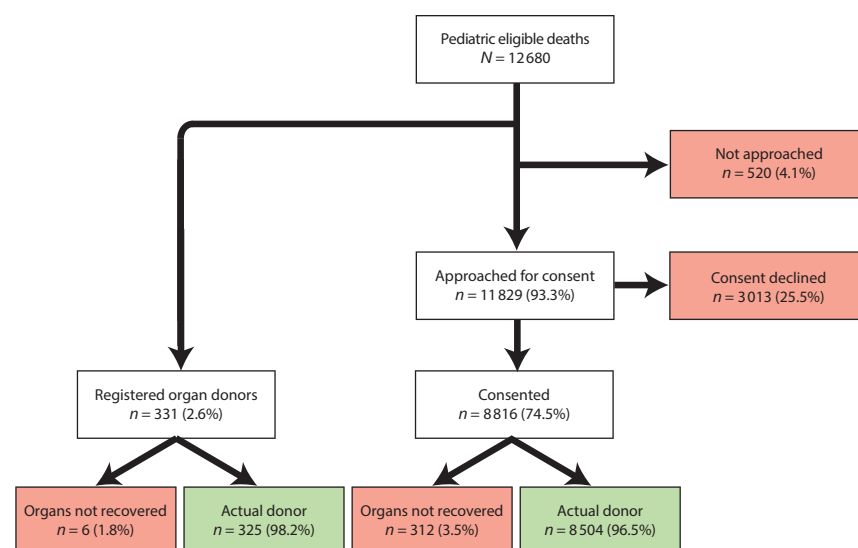


FIGURE 1

Flowsheet of pediatric eligible deaths.

patients were approached less often. There was also high variability across OPOs in the rate of not approaching families to request consent (range 0%–12.6%) (Supplemental Fig 6).

Characteristics of those who did and did not consent for organ donation are shown in Table 2. Characteristics associated with refusing consent for organ donation include age <1 year (27.9% vs 25% for other age groups; $P = .009$), female sex (26.5% vs 24.9%; $P = .05$), people of color (20.7% refusal for white race versus 34.9% for Black, 45% for Asian, and 39.7% for other race; pairwise $P < .001$ for all versus white race), Hispanic ethnicity (28.1% vs 24.8%; $P = .001$), lower median household income (\$45 625 vs \$47 218; $P < .001$), and lack of a timely referral to the OPO (32.9% vs 24.5%; $P < .001$). Circumstances of death were also

associated with consent rate, with eligible deaths from suicide and child abuse revealing the highest donor consent rates. Linear regression analyses reveal a decrease in pediatric donor consent rates over the past 10 years (Fig 2) despite a consistent number of eligible pediatric deaths annually (Supplemental Fig 7). Pediatric donor consent rates are directly related to subject age (Supplemental Fig 8) and consistently lower than adult consent rates observed among the 43 575 eligible adult deaths analyzed (Supplemental Figs 9 and 10). There is significant variability in pediatric donor consent rates across OPOs (Fig 3), with increasing variability in younger patient groups (SD of consent rates across OPOs: <1 year: 11.5%; 1–4 years: 11.7%; 5–10 years: 11.7%; 11–17 years: 6.0%). This is in contrast to adult donors, for which

donor recruitment is more consistent across OPOs (SD of consent rates across OPOs: 18–40 years: 4.5%).

The factors independently associated with consent for organ donation in a multivariable logistic regression model include subject age, race, ethnicity, child abuse etiology, a timely referral to the OPO, and the recruiting OPO (Table 3). Revealed in Figure 4 is the probability of consent for organ donation by OPO after adjusting for confounding factors in a multivariable logistic regression model, with SE estimates adjusted for clustering within OPOs. A similar high degree of variability was seen in consent rates across OPOs when the analysis was repeated after excluding eligible deaths of white race (Supplemental Fig 11). Adjusted and unadjusted results by OPO are presented in Supplemental Table 4.

TABLE 2 Donor Characteristics Based on Consent ($N = 11\,829$)

	Consented <i>n</i> = 8816 (74.5%)	No Consent <i>n</i> = 3013 (25.5%)	P^a
Age group, y, <i>n</i> (%)			<.001
<1	1366 (72.1)	528 (27.9)	
1–4	2074 (72.4)	789 (27.6)	
5–10	1392 (73.2)	509 (26.8)	
11–17	3984 (77)	1187 (23)	
Sex, <i>n</i> (%)			.05
Male	5502 (75.1)	1820 (24.9)	
Female	3314 (73.5)	1193 (26.5)	
Race, <i>n</i> (%)			<.001
White	6446 (79.3)	1683 (20.7)	
Black	2075 (65.1)	1110 (34.9)	
Asian	154 (55)	126 (45)	
Other	141 (60.3)	93 (39.7)	
Ethnicity, <i>n</i> (%)			.001
Hispanic	1763 (71.9)	689 (28.1)	
Non-Hispanic	7053 (75.2)	2324 (24.8)	
Timely referral, <i>n</i> (%)			<.001
Yes	7864 (75.5)	2547 (24.5)	
No	952 (67.1)	466 (32.9)	
Circumstances of death, <i>n</i> (%)			<.001
Motor vehicle crash	1932 (77.1)	573 (22.9)	
Suicide	897 (84.8)	161 (15.2)	
Homicide	566 (72.6)	214 (27.4)	
Child abuse	1084 (78.5)	297 (21.5)	
Accident, not a motor vehicle crash	1442 (75.9)	459 (24.1)	
Natural causes	1764 (69.8)	762 (30.2)	
None of the above	1122 (69)	504 (31)	
Household income, ^b \$, median (interquartile range)	47 218 (38 244–60 122)	45 625 (35 502–57 654)	<.001

^a P values from the χ^2 test for categorical and the Wilcoxon rank sum test for continuous data.

^b Based on donor home zip code and 2010 US census data. $n = 9683$ (18.1% missing).

DISCUSSION

With this study, we highlight a number of unique aspects of pediatric deceased organ donation. The Organ Donation Breakthrough Collaborative has resulted in an increase in the number of adult organs available for transplant, largely through efforts aimed at increasing organ donor registration. However, the number of pediatric deceased donors has decreased over time.^{1–4} Our study reveals that this decline may be attributable to an overall decrease in consent rates among potential pediatric donors and is less likely related to changes in the number of eligible pediatric deaths. Increased OPO reliance on organ donor registration in the adult population may negatively impact requestor proficiency with the consent process, contributing to this decline. Furthermore, whereas conversion rates for adult donors appear consistent across OPOs, OPOs vary widely in their consent rates for pediatric donors. This pattern suggests that the optimal recruitment

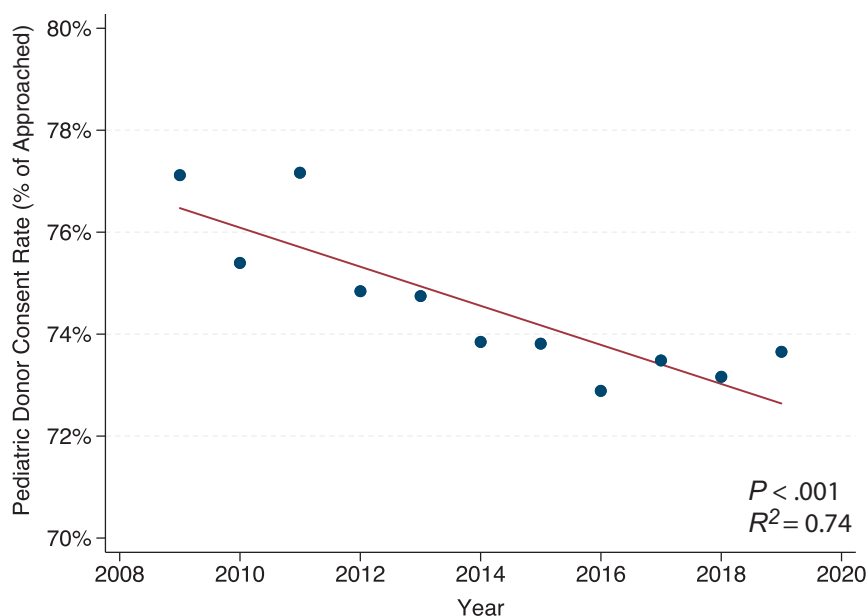


FIGURE 2

Pediatric deceased donor consent rate over time ($N = 11\,829$ eligible deaths approached to request consent).

practices for adult donors may not be applicable to pediatric donation and that some OPOs may be using more effective pediatric recruitment techniques than others. In fact, it is suggested in recent data that there are modifiable aspects of the consent process that impact donor decision-making in the pediatric population.^{13,14} Sharing the best practices from high-performing OPOs may be a successful strategy to optimize pediatric donor recruitment nationwide.

There are inherent differences between organ donation in children compared with adults. The implementation of organ donor registries has resulted in a meaningful increase in the number of deceased organ donors, with nearly 40% of adults ≥ 18 years of age being present on a donor registry.^{15,16} However, this mechanism for donor recruitment is largely inaccessible to the pediatric population. Consistent with this, $<3\%$ of all eligible pediatric deaths were registered as organ donors in our study. The vast majority of individuals who register as an

organ donor do so through the department of motor vehicles,¹⁷ leading to a number of targeted interventions to improve registration rates^{17–19} but excluding the majority of children and adolescents. Although adolescents may use this mechanism to register with the intent of being an organ donor when undertaking driver training, it is not legally binding and a parent or guardian must make the final determination of authorization for organ donation to occur.²⁰ For this reason, next-of-kin consent is required for virtually all pediatric deceased organ donors. In the adult population, next-of-kin decision-makers are more likely to have discussed the decedents beliefs and wishes surrounding organ donation, whereas this is unlikely in the pediatric population. Therefore, organ donation decisions in the pediatric population are likely based largely on the next-of-kin beliefs and opinions regarding transplantation and organ donation amid grieving at the loss of their child or loved one.

Our results reveal that several donor-specific factors are associated with

pediatric organ donor consent, with socioeconomic factors playing a large role. This finding is consistent with previous studies that highlight the impact of race and family educational attainment on organ donation decisions.^{21–27} Although some of the factors associated with nonconsent may not be modifiable, knowledge of these characteristics may impact the approach to requesting organ donation because the optimal strategy may vary on the basis of donor demographics.^{28–30}

Importantly, the profile of potential donors who were not approached for consent largely mirrored the characteristics associated with refusal of consent. This suggests that OPOs may have a preconception of the willingness of a family to donate on the basis of patient demographics, potentially leading to systemic biases that impact practice. One notable exception is eligible deaths secondary to child abuse. This group was less likely to be approached for consent but more likely to agree to organ donation when approached. Implementing policies directed at approaching all families or next-of-kin of all eligible pediatric deaths may help to increase the availability of pediatric donor organs and reduce any potential bias in who is approached for consent, whether intentional or not, by OPO staff.

The results of our analysis have potential implications for health equity and disparities. In our analysis, race and ethnicity were independently associated with consent rates, and similar findings have been reported in the adult population.^{24,27,28,31} Previous studies have revealed suboptimal communication with Black families during the consent process whereby they are approached less often, presented with less information, and have a less favorable impression of the donation request.^{28,32} Therefore, it is not surprising that Black families report greater mistrust in the equity

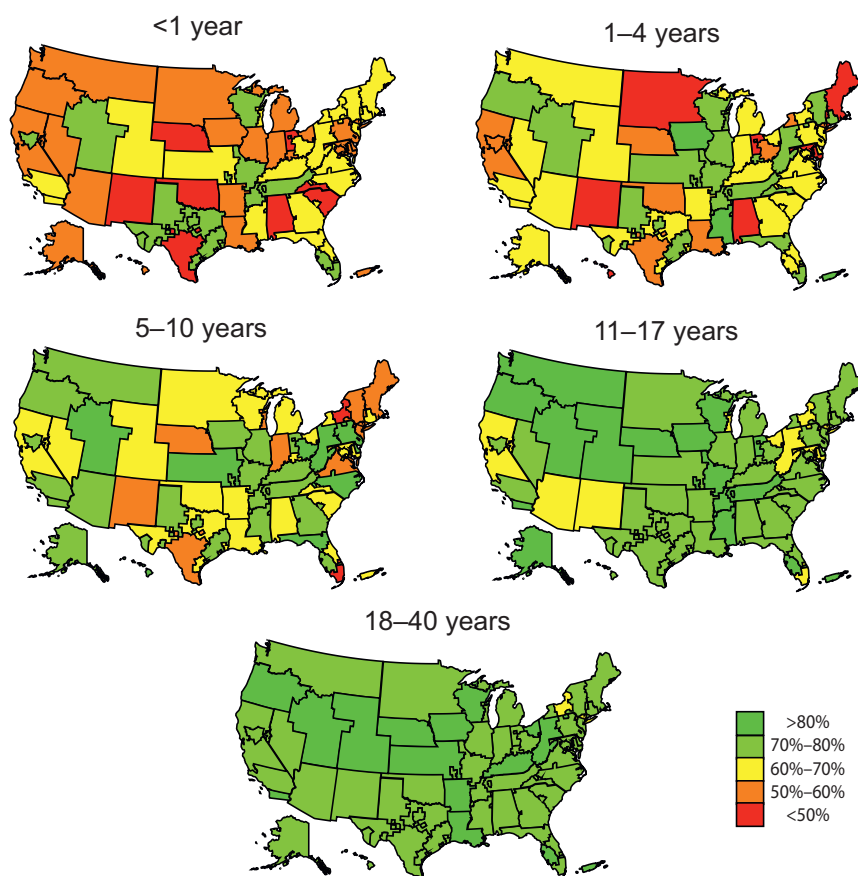


FIGURE 3
Regional variation in pediatric consent rates by subject age group.

of organ donation, have varying opinions regarding incentivization to donate, and express less favorable

attitudes toward organ donation and health care systems.^{27,28} Our data reveal that there is also a high degree

TABLE 3 Multivariable Logistic Regression Model: Factors Associated With Consent for Donation

	Unadjusted Odds Ratio (95% CI)	P	Adjusted Odds Ratio (95% CI)	P
Age, y	1.03 (1.02–1.03)	<.001	1.03 (1.03–1.04)	<.001
Male sex	1.09 (1–1.18)	.05	1.06 (0.97–1.15)	.186
Race				
White	Referent	Referent	Referent	Referent
Black	0.49 (0.45–0.53)	<.001	0.39 (0.33–0.45)	<.001
Asian	0.32 (0.25–0.41)	<.001	0.27 (0.22–0.35)	<.001
Other	0.4 (0.3–0.52)	<.001	0.37 (0.25–0.54)	<.001
Ethnicity				
Hispanic	0.84 (0.76–0.93)	.001	0.54 (0.45–0.64)	<.001
Non-Hispanic	Referent	Referent	Referent	Referent
Timely referral to the OPO	1.51 (1.34–1.7)	<.001	1.35 (1.17–1.57)	<.001
Child abuse etiology	1.26 (1.1–1.45)	.001	1.68 (1.44–1.97)	<.001
Median household income (per \$10k)	1.09 (1.06–1.12)	<.001	1.03 (0.98–1.07)	.291
Year	0.99 (0.97–1.0)	.02	0.99 (0.97–1.02)	.497
OPO	See Fig 4 ^a	See Fig 4 ^a	See Fig 4 ^a	See Fig 4 ^a

CI, confidence interval.

^a Adjusted and unadjusted results for OPO are presented in Supplemental Table 4.

of variability in consent rates across OPOs in minority groups, again suggesting that some OPOs employ more effective donor recruitment strategies than others. The presence of a language barrier may also influence the consent process and contribute to the impact of race and ethnicity. However, the SRTR database does not collect data pertaining to language proficiency of families or requestors and therefore this cannot be directly assessed in our analysis. It is important to consider that OPO processes and the potential for systemic racial biases could contribute to the impact of race and ethnicity on consent rates, representing an important area for future research. Critically, these socioeconomic and racial determinants of organ donor consent may translate into a lack of access to life-saving organ transplants in already disadvantaged regions and groups.

Communication is consistently cited as a major factor impacting family decisions surrounding organ donation.^{14,19,21,33–35} Requests that are viewed as being “sensitive,” those “with optimal timing,” and requests that provide families with sufficient time to make a decision are more likely to be successful.^{13,35} However, who approaches the family may also influence the decision-making process. A study by Rodrigue et al¹³ revealed that organ donor consent was more likely to be successful when donation was first mentioned by a member of the medical team. In a separate study, researchers documented improved consent rates when the family was approached by an OPO coordinator.³⁵ However, sex and race of the requestor may also impact decisions, and consent rates may be optimized with requestors from similar demographic backgrounds as the family decision-makers.³⁶ Given the notable differences between organ donation in children compared with adults, it is

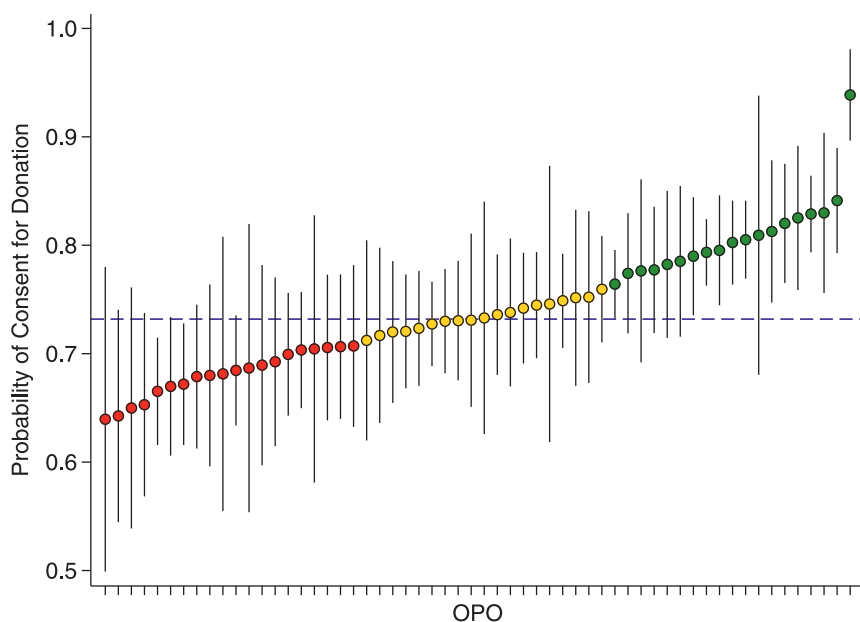


FIGURE 4

Probability of organ donation consent by OPO after adjusting for year, age, median household income, race, ethnicity, circumstances of death, sex, and timely referral. Bars represent the 95% confidence interval. The reference line represents the median probability of donation across all OPOs. Red, yellow, and green markers indicate the first, second, and third tertiles, respectively.

unclear if the optimal communication practices are the same between groups. Currently, there are limited published data to support specific communication strategies that optimize consent rates in the pediatric population, representing an important area for future research.

The results of our study suggest that OPO-specific factors play a role in organ donation consent rates, independent of regional demographic differences. Therefore, identifying best practices for pediatric donor recruitment through in-depth examination of practices from high-performing OPOs and developing standardized training approaches across OPOs represents a potential strategy to increase the number of pediatric organs available for transplant. This strategy mirrors the highly successful approach employed by the Organ Donation Breakthrough Collaborative.¹ Current annual

reports as well as OPO-specific reports published by SRTR do not separate pediatric donor statistics from adults.^{5,37} Our study also highlights the importance of including pediatric-specific data when evaluating OPO performance because this provides valuable insights to guide future improvements in pediatric deceased donor recruitment.

There are inherent limitations to our study. We only included eligible deaths to be consistent with reports of OPO performance published by SRTR.⁵ However, this does not account for other potential routes to pediatric organ donation such as donation after circulatory death. Although we used available demographics within SRTR to adjust for socioeconomic and demographic differences that may impact organ donation, there may be additional donor factors outside what is

captured by SRTR that impact donation decisions. Our analysis suggests the presence of OPO-specific factors that influence the organ donation process; however, the specific factors leading to the differences in donor recruitment remain unknown. Although previous data suggest that the demographic background of individuals requesting consent influences success of the consent process,³⁶ details of OPO requestor sex and race are not available in the SRTR data set. Additionally, it is possible that the differences noted are influenced by hospital-specific factors (ie, children's hospital versus community hospital or ICU versus non-ICU care) that are independent of OPO performance. This represents an important area for future investigation.

CONCLUSIONS

Organ donor consent rates are lower in the pediatric population compared with the adult population with high variability across OPOs and on the basis sociodemographic factors. OPOs are independently associated with the rate of successful pediatric donor consent with clear high- and low-performing regions. Standardization of practice across OPOs and the sharing of best practices has the potential to improve authorization rates, which in turn may increase the availability of pediatric donor organs for transplant nationwide.

ABBREVIATIONS

OPO: Organ Procurement Organization
OPTN: Organ Procurement and Transplantation Network
SRTR: Scientific Registry of Transplant Recipients

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